

# Exploring the Experiences of Parental Cancer among Young Adults

Pranathi Harihar\* and Anuradha Sathiyaseelan

**Abstract**—The study aimed to understand the changes in the parent-child relationship after the diagnosis of a parent with cancer, explore the psychological and emotional challenges faced by young adults, gain insight into the strategies these young adults used to cope, and create intervention strategies to provide psychosocial care to the young adults whose needs go unmet. Participants were young adults between 18 and 24, three males, one non-binary, and three females. The research design was of qualitative methodology. Seven in-depth interviews of 20 – 45 minutes each were conducted in a semi-structured format, both online and offline. The data was analyzed using Thematic Analysis. The main themes identified were Dynamics in Parent-Child Relationships and Communication, Challenges Faced by Young Adults, and Managing to Face the World and a Way Forward. Fear, shock, anger, and sadness were common reactions to hearing the parent’s diagnosis. They reported a stronger relationship with the parent post-diagnosis. The majority expressed the importance of therapy and support groups to help cope during these turbulent times. The results can be utilized to formulate a psychosocial intervention for young adults with parental cancer to reduce the psychological and emotional burden on them.

**Index Terms**—Psychological, emotional, changing relations, parental cancer, young adult’s experiences, challenges

## I. INTRODUCTION

Exploring The Experiences of Parental Cancer Among Young Adults “Cancer didn't bring me to my knees. It brought me to my feet” (Michael Douglas, 2012). Cancer, a disease caused by excessive tissue proliferation, reached an estimated 18.1 million cases in 2020 [1]. Diana Baumrind’s Parenting Styles and John Bowlby’s Attachment Theories might seem altered after a parent’s cancer diagnosis as treatment consumes most of a parent-child relationship. Cancer disrupts not just the patient’s life but also the family members. The patients, burdened with treatment and other responsibilities, might unconsciously and unintentionally neglect the child’s needs, causing emotional and psychological distress.

According to a cohort study by Wallin *et. al* (2018), adjustment disorders were more common among children/adolescents aged 13 and older. This study, thus, aims to understand the impact of parental cancer and the obstacles that young adults face. It would also help us identify areas where young adults need psychosocial assistance or support.

A literature review of studies exploring an offspring’s reaction to their parental cancer showed impaired emotional

and behavioural aspects in young adults as a common pattern.

Studies showed how a child’s physiological, emotional, and school well-being were significantly impaired [2], parental cancer as a significant risk factor for children’s use of specialized psychiatric services [3], significantly similar levels of anxiety and depression by comparing parental cancer and parental death [4], and uncertainty and loneliness to be strongly linked to teenage emotional and behavioural functioning [5]. Studies brought to light that youngsters frequently encounter emotional issues and lack understanding and communication [6], low resilience and physical fitness in male young adults [7], and denial, behavioural disengagement, substance use [8], distraction, preserving normalcy, with greater duties and decreased social activities [9] as coping mechanisms. Parents being oblivious to their adolescent children’s stress and overpowering sentiments of despair and anxiety [10], an impact on the psychosocial functioning of children [11], and challenges in areas like emotional reactions, family issues, friendships, and school [12] were revealed in studies. The study aimed to understand the changes in the parent-child relationship after the diagnosis of a parent with cancer, explore the psychological and emotional challenges faced by young adults, gain insight into the strategies these young adults used to cope, and create intervention strategies to provide psychosocial care to the young adults whose needs go unmet.

## II. METHOD

**Research Design:** The research adopted an Interpretative Phenomenological Analysis, a qualitative approach. **Sampling:** Purposive Sampling was used to select participants in relation to the phenomenon being studied. **Participants:** Four males, three females, and one non-binary participant who were young adults between 18 and 24, had experienced parental cancer, and had been a part of the treatment process were included. **Data Collection:** An interview guide was developed and validated. Informed consent forms were given to participants before the interview. Semi-structured interviews of 20–40 minutes were conducted online, and the audio was recorded. A reflective journal was maintained after each interview, and memo questions were developed to clarify information with the participants. **Data analysis:** Braun and Clarke’s Thematic Analysis method was used. The transcription of all audio files, followed by member checks, was completed. To become familiar with the data, the transcripts were read multiple times. Common terms and patterns were identified. Initial codes were generated and organized into basic, organizing, and global themes. The themes were reviewed before producing the final analysis. **Ethical Considerations:** The data collected through interview sessions were maintained with confidentiality. Access was

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only provided to the research supervisor. The research study is then given for publication in a journal. Presentations in seminars will be done. The identity of the participants will

not be revealed. Confidentiality of data is the highest priority. The research is IRB approved (see Fig.1).

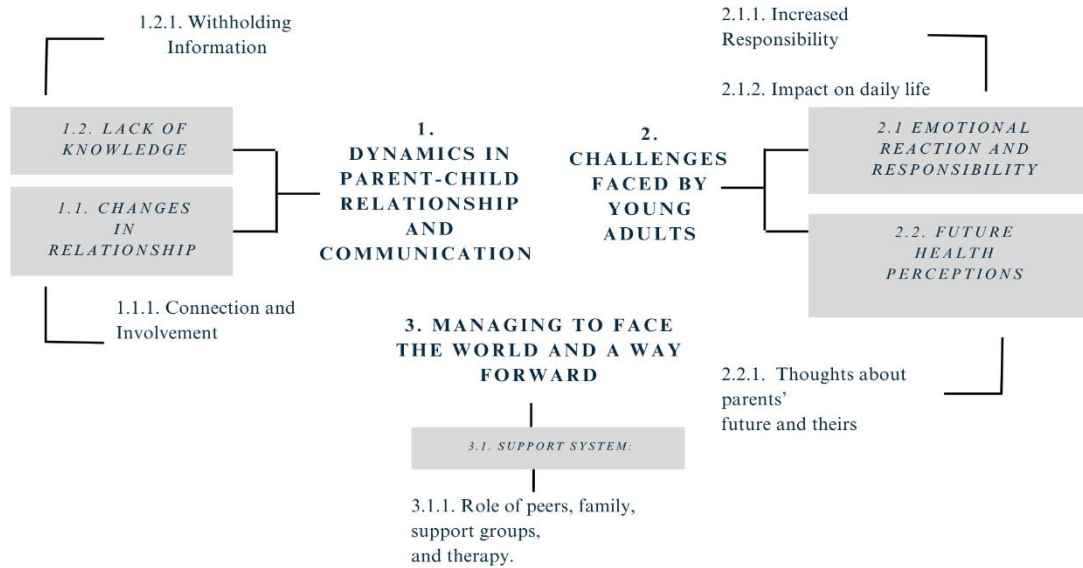


Fig. 1. Mind map of thematic analysis.

### III. RESULTS

The participants had parents with cancer diagnoses like Hodgkin’s Lymphoma, Leukemia, Breast, Throat, and Vulvar Cancer. The analysis produced three themes.

#### A. Dynamics in Parent-Child Relationship and Communication

A parent-child relationship is a unique and dynamic interaction involving both parties, vital to young adults’ emotional and mental development [13]. Researchers found that four participants grew closer to their parents and strengthened their bond. One participant had difficulty finding closeness. Two participants also mentioned a lack of communication and how they were uninformed about the diagnosis and treatment.

##### 1) Changes in relationship

Young adults reported either a positive or a negative change in relationship dynamics. Researchers could understand that six participants noticed only an improvement in their relationships with their parents. However, one participant had difficulty building a connection with his mother after losing his father to cancer. Some temporary changes were noticed, but no long-term effect was reported [14].

##### a) Connection and involvement

“Relationship dynamic changed... less of a baby to her... didn’t drift” (P7, Personal Communication, 2022). Participants highlighted how the relationships were strengthened for some, but others noticed how they remained the same. Researchers could notice an already existing bond between the parent and the young adult that was only improved post-diagnosis. “We were very close... do many activities... Ever since this happened... all down the drain”

(P1, Personal Communication, 2022). However, two participants highlighted reduced bonding activities they would do before, like photography and watching movies. They also reported a lack of involvement as one participant had to care for her sibling alone, and another was looked after by his grandmother.

##### 2) Lack of knowledge

Open communication was missing, giving young adults partial knowledge [15]. Researchers could understand how pre-teens to early adolescent participants felt that information was not shared with them during their parent’s treatment. Some mentioned not even being aware of the term ‘cancer’. Immediately upon hearing the diagnosis, there was shock and anger. Eventually low mood and sleep disturbances were reported that was maintained due to uncertainty and lack of information.

a) Withholding information: “keeping stuff from me for my safety” (P2, personal communication, 2022)

Some participants explained feeling frustrated, confused and lost due to a lack of understanding of what was happening with their parents. “Lot more sensitive, supportive & empathetic... help more than medicine.” (P7, Personal Communication, 2022). Participants explained how the best way to make the situation easier would have been to completely know the condition, along with more time and effort from the doctors. Researchers could understand the importance of educating young adults about their parent’s condition.

#### B. Challenges Faced by Young Adults

Due to the significant impact of parental cancer on young adults, *challenges* referred to relationships and psychological threats [16]. Researchers could find an immediate response to anger, fear, and sadness. They found it difficult to accept

the situation. Most reported having an emotionally strong parent, but the participants provided positive encouragement and support. Some participants had no choice but to take care of their parents and be present during treatment.

### 1) Emotional reaction and responsibility

Responsibility means taking up roles emotionally and practically to reduce parents' stress [17]. Quality of Life was seen to be impacted due to health and psychological needs that went unmet during parental cancer [18]. Anger, guilt, fear, adjustment pain, sadness, shock and an equal chance of acceptance or non-acceptance of the disease forms an Emotional Reaction [16].

#### a) Increased responsibility

"Everything was on me even... stressful... added responsibilities" (P6, Personal Communication, 2022). They mentioned that at a young age they were expected to do a lot and more, like taking care of hospital bills, interacting with doctors, filling up insurance forms, understanding the treatment and the prognosis etc.

"She asked me to come with her to the hospital... I started avoiding the question... I didn't want to see my mom go through that" (P7, Personal Communication, 2022). However, this one participant reported avoiding hospital visits with his mother because he did not want her to endure so much pain and hardships. Researchers could understand that the participants took charge and did what was needed of them during that period – they had no choice but to calm the parent down and stay positive.

#### b) Impact on daily life

"Made sure I was busy enough... would not think or feel anything... pack my day... tire myself out... I just come home and sleep" (P7, Personal Communication, 2022). Participants reported having an emotional impact, like being scared, upset, withdrawing, and disconnecting. They also used distracting techniques to keep themselves busy and avoid overthinking by going on walks, listening to music, painting, etc. "A very big question for me. Why my mom?" (P3, Personal Communication, 2022). Participants reported not understanding whether they were just in denial, whether acceptance became easier due to supportive family and relatives, and that the side effects of chemotherapy changed the entire narrative. "Two months was very stressful... didn't perform in weekly tests or didn't attend classes... was nervous... wanted to be at home with her" (P4, Personal Communication, 2022). There was extreme stress, and maintaining attendance was an issue. "Would sit there and study... lucky that it was time of covid" (P5, Personal Communication, 2022). However, one participant mentioned that he used to balance his work well at the hospital". Two participants reported being clinically depressed.

### 2) Future health perceptions

The perceived risk of developing cancer and presence of avoidance and unpleasant thoughts [19]. Fear or cancer recurrence and a constant worry is a significant challenge faced by cancer survivors [20]. The young adults also often express worry about developing the disease themselves and a fear of recurrence associated with their parent [21].

#### a) Thoughts about parents' future and theirs

"A shift of lifestyle... moderation and restrictions on

food... a routine lifestyle" (P4, Personal Communication, 2022). All the participants expressed concern about their parent's future and health but mentioned the uncertainty regarding cancer. They mentioned the fear associated with the risk of recurrence but were hopeful and wished for a healthy future. Researchers could understand that although participants were concerned about their parent's recurrence and their risk of developing cancer, they were positive. They mentioned how it is inevitable and how going through it with their parents once has prepared them.

### C. Managing to Face the World and a Way Forward

The benefits of psychosocial interventions and support services were understood and actively utilized by cancer patients [22]. Despite its extreme need, there is limited psychosocial care for the children of a parent with cancer [23]. Researchers could understand the importance of psychosocial intervention at crucial times, which could prove helpful through the journey of cancer.

#### 1) Support system

Parental cancer impacts young adults in ways that lead to various adjustment responses [24]. Coping strategies were ways in which adolescents dealt with their psychological and emotional concerns [8]. The participants expressed the need to be able to share their emotions and thoughts with peers. The participants said that spending time with family and maintaining normalcy was key.

#### a) Role of peers, family, support groups, and therapy

"Being able to talk to my friends, building support with friend groups" (P2, Personal Communication, 2022). "Family time... best way to cope" (P6, Personal Communication, 2022). Participants expressed positive views about support groups as they felt that being around people with similar experiences would make it easier for them. "Knowing that you're not alone... the things others are doing... helpful insight into your situation" (P2, Personal Communication, 2022). They said it would help ease the confusion regarding their parent's diagnosis and treatment. It would help them vent as it would be easier to talk to strangers, which is what some of them felt. Participants also shared how having a professional therapist to guide them and allow them to talk about their emotions would help prevent many things in the future and be extremely helpful.

## IV. CONCLUSION

Overall, it can be noticed that many needs of young adults go unmet when a parent gets diagnosed with cancer. They go through an ocean of emotions and challenges. But they all did believe that they saw some growth in themselves. The study's limitations are that it might be biased due to the expected outcomes of the research. The study's wide age range does not give specific results to one age group. There were no restrictions on the age at which participants experienced parental cancer, which to some extent, varied their experiences. The study was also limited to India and might not allow generalization to other cultures. No gender differences were studied, and it did not focus on one type of cancer. The study implies formulating a psychosocial intervention for young adults battling parental cancer.

Various ways of social support, like support groups and therapy, can be found to reduce the psychological and emotional burden on young adults whose needs often go unmet. It helps Mental Health Professionals identify target areas for their therapeutic intervention. The study highlights the challenges and needs of young adults that should not be ignored by parents and family as well. For future direction, gender differences causing different experiences should be investigated. Personality traits influencing their coping styles and experiences and attachment styles can be explored further.

#### CONFLICT OF INTEREST

The authors declare no conflict of interest.

#### AUTHOR CONTRIBUTIONS

Pranathi Harihar conducted the research by carrying out the interviews and doing the transcription. She, under the guidance of Anuradha. S, analyzed the data, developed themes, and wrote the paper. All authors had approved the final version.

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